

OPTIMIZING CLINICAL OUTCOMES with PATIENTS with PKU or CAREGIVERS through PATIENT-CENTERED COMMUNICATION and WORD CHOICE

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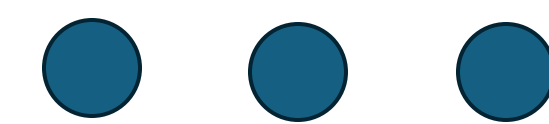
Words, Phrases and Suggested Options from a Sample of Individuals Living with PKU or Caregivers

WORDS/PHRASES TO AVOID	PREFERRED WORDS OR PHRASES
Control	Range
Good Foods or Bad Foods	High PHE Foods; Low Protein Options or Food
Noncompliance	Barriers to Diet Management; High PHE Diet Intake
Failure	Struggle; Need to Reset; Education Needed
Brain Damage	Neurological Impact
Bad Levels	Levels Out of Range
Mismanaged	Education; Patient Tools, Resources Needed
Normal	Therapeutic Goal when Discussing PHE; Meeting Individual Physiological Needs
Adherence	Sustaining; Ability to Manage Intake
Failed Diet or Failed Treatment	Need for Additional Tools, Education, Resources
Lost to Follow-Up	In Need of Clinical Support
Abnormal or Abnormality	Not within Desired Goal Range or Not Ideal; Outside of Established Range
Diet for Life	Lifelong PKU Management; Healthy Eating for PKU
Food Restrictions	Limit High Protein/PHE Foods; Food Choices
Yes/No Foods	High/Low PHE Foods
Tube Feeding	Enteral Nutrition; Alternative Nutrient Delivery Method
Picky Eater	Selective Eater; Food Aversion; Limited Food Choices; Need to Expand Food Choices
Clinic Rules	PHE Management Guidelines and Standards
Chronic Disease	Lifelong Condition

OTHER PREFERRED PHRASES

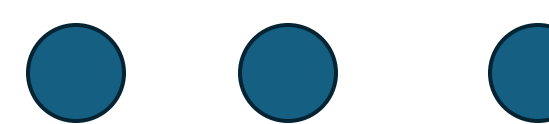
Manage Nutritional Intake
 Balance PHE, Protein Equivalent and Caloric Intake
 Different Formula Intake Options
 Eating Healthy Protects my Brain
 PHE Diet Management Guidelines and Standards
 Managing Health through Proper Nutrition
 Enhancing Cognitive Function
 Food/Formula as Medicine
 Optimum Health

INTRODUCTION:



- Words are singularly the most powerful force available to humanity and play a crucial role in healthcare communication, particularly for individuals living with lifelong conditions like Phenylketonuria (PKU) who have frequent clinic visits and require individual responsibility to follow a lifelong regime.
- Drawing from literature and the National PKU Alliance Mentor Program, we highlight the significance of patient-centered language in fostering trust, understanding, and collaboration between patients and healthcare providers (HCP).
- This pilot study explores the impact of language used by (HCP) on patient outcomes and suggests strategies to improve communication in PKU care.
- The purpose is to offer suggestions of word preferences and phrases to HCPs in hopes of working in a collaborative relationship that builds trust and improves outcomes.

BACKGROUND:



- An HCP ability to effectively and compassionately communicate information is key to a successful relationship. Over time, medical understanding and knowledge have evolved.
- Language used to communicate about chronic conditions also evolved to de-stigmatize and to the change of medical terms to more neutral or respectful terms; a shift towards more patient-centered communication.
- Patient-centered communication is an approach to interacting with patients that places their needs, preferences, and values at the center of the conversation and helps improve patient outcomes. It involves:
 - Choosing words that optimize the health outcome while utilizing patient-centered communication elements, such as:
 - Active listening, empathy, respect, inclusiveness, and open-ended questions.
 - Moves communication from a physician-centered to a patient-centered visit using word preferences that will improve the efficiency and effectiveness of the clinical visit.
- Language HCP use with patients and their caregivers can lead to poor health outcomes or resistance to treatment.
- Use of jargon, technical terms, or medical language that the patient does not understand can create confusion and mistrust.
- If HCP uses a dismissive or condescending tone it can create feelings of frustration or alienation in the patient, which can also lead to resistance or variability in their treatment plan.
- Using discriminatory language can make the patient feel uncomfortable or disrespected and may contribute to feelings of shame, embarrassment, and marginalization, which can negatively impact their health and well-being.

METHOD:



- An open-ended survey requesting word and phrases
- A small pilot study through (N=28) using a survey emailed to adults with PKU from the NPKUA Peer Mentor Program.
- Mentors identified and submitted words and phrases perceived as stigmatizing in healthcare context.

RESULTS:



- Majority of mentors agreed with and provided alternative words and phrases.
- Findings emphasize that words evolve over time, and language that may have been neutral in the past can become stigmatizing.
- HCPs may consider recognizing changes in language preferences among patients and adapt their communication accordingly.
- Trust is identified as a critical factor influencing communication between patients and healthcare providers, emphasizing the importance of building rapport through empathetic and compassionate language.

IMPLICATIONS AND FUTURE DIRECTIONS:



- This pilot study emphasizes the transformative potential of patient-centered communication in PKU care.
- By adopting language that respects patient preferences and values, HCPs can enhance patient understanding, empowerment, and commitment to treatment.
- This provides valuable insights and underscores the need for further research and implementation of personalized approaches to healthcare communication.
- These insights highlight the need for sensitivity to language choices in clinical settings regarding discussions about Phe levels and symptom management. Substitutions of stigmatizing language with neutral or positive alternatives were suggested to foster a more collaborative patient-physician relationship.
- Recognizing cultural and linguistic backgrounds will break barriers as a possible factor in improving recommended treatment.
- The study highlights the importance of HCPs using clear, non-stigmatizing language when interacting with PKU patients. Patient-centered communication, characterized by empathy, respect, and inclusiveness, is essential for optimizing patient outcomes and promoting patient engagement in their care.
- Positive, and meaningful interactions contribute to improved patient well-being, satisfaction with care, and health outcomes.

CONTACTS:

- National PKU Alliance | www.NPKUA.org
- For PKU by PKU | Adult Mentor Program

